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COVID-19 and Its Influence on Prevalence of Dementia and Agitation in Australian Residential Age Care: A Comparative Study

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Abstract: The COVID-19 pandemic profoundly impacted older people in residential aged care facilities (RACFs), especially those with dementia. This retrospective cohort study investigates the impact of the pandemic on agitation incidents within this population in 40 Australian RACFs. We compared pre-pandemic data (January-October 2019) with during-pandemic data (same months in 2020 and 2021) from electronic health records (EHRs) using Python to extract information from nursing notes. Various statistical analyses, including descriptive statistics to summarize the data, and a chi-square test to examine any significant association between the COVID-19 pandemic and the prevalence of dementia and agitation in dementia. Dementia prevalence dropped by 1.98% in 2021 compared to 2019, and by 4.09% compared to 2020 ($p < 0.05$). Overall agitation symptoms decreased by 20.1% from 2019 to 2021 ($p < 0.05$), but six specific symptoms increased: resisting (28.98%), wandering (11.78%), restlessness (3.19%), complaining (10.1%), arguing (2.36%), and outbursts (1.74%) ($p < 0.05$). Conversely, pacing decreased by 15.88% and speaking loudly decreased by 10.9% ($p < 0.05$). Over half of the care recipients experienced agitation symptoms 2-5 times each year, increasing from 50.56% in 2019 to 58.28% in 2021 ($p < 0.05$). It is important to exercise caution regarding the accuracy of these findings due to the reduced opportunity for busy care staff to record behavioral changes caused by the isolation of individuals in their rooms during the pandemic.

Keywords: COVID-19; dementia; agitation; residential aged care; nursing home; electronic health record; natural language processing

1. Introduction

The COVID-19 pandemic has had a profound impact on our society. As of January 21, 2024, the World Health Organization documented an overwhelming 775 million cases worldwide [1]. From February 2020 to December 2021, Australia experienced three waves of the COVID-19 pandemic, with progressively increased levels of severity [2]. The first wave occurred in March-April 2020, the second in July-September 2020, and the third commenced in August 2021, and has continued into December and beyond [3,4]. The correlation between mortality and advancing age is well-established [5], and this risk is further compounded by concurrent comorbidities [6]. For example, in Canada, the COVID-19-related mortality rate within residential aged care facilities (RACFs) constitutes almost 80% of the national mortality rate. Similarly, in Switzerland, RACFs account for 50% of COVID-19-

related deaths [7]. In Australia, a staggering 75% of all COVID-19-related deaths occurred within RACFs from January 2020 to March 2021 [8].

Dementia, characterized by progressive cognitive decline and memory impairment, imposes a range of challenges in addressing unmet needs within RACFs. A study across 185 countries found a significant correlation between deaths of people with dementia (PWD) and COVID-19 cases [9]. This finding is further verified by data from an Acute Hospital in Brescia Province, Northern Italy, where PWD experienced a significantly higher mortality rate at 62.2%, which was 36% higher than the 26.2% mortality rate for the non-dementia population [10]. In Australia, PWD accounted for 30% of COVID-19 deaths during the first 10 months of 2020. These individuals were often residents of RACFs that experienced an outbreak [11]. The Australia Institute of Health and Welfare (AIHW) reported that around 54% of RACF care recipients were diagnosed with dementia during COVID-19 in 2021-2022 [12]. Of these, approximately 84% required high levels of care due to cognitive impairment, wandering tendencies, verbal and physical behaviours, and depression [13]. They accounted for 75% of all COVID-19-related deaths in RACFs [8].

Agitation, observed in 70%–80% of PWD living in RACFs [14], encompasses manifestations of disturbed perception, thought, mood, or behaviour [15]. Agitated behaviours include, but are not limited to, restlessness, pacing, yelling, attempts to access inappropriate places, resistance to care, physical aggression, verbal disruption, and inappropriate sexual behaviour [10,16–19]. Agitation is triggered by many factors, including pain, discomfort, anxiety, fear, frustration, disruption in routine, unfamiliar environment, and sensory overload [20]. Agitation limits PWDs' ability to communicate their needs, comprehend their surroundings, adjust their behaviours and seek help [21]. These symptoms and their frequency increase with the progression of dementia, specifically during the COVID-19 pandemic [22]. Strategies applied in RACFs to manage agitation include redirection, repositioning, psychotropic medication, reassurance, routine care practices, and offering of beverages [23]. All these methods require care staff to have a close personal interaction with care recipients, incorporating the input of physicians, allied health clinicians, behavioral therapists, and care recipients' substitute decision-makers [24].

The ensuing impact of the COVID-19 pandemic and its associated restrictions has been substantial, affecting RACFs, their resident care recipients, and care staff [4,25]. In May 2020, Australian RACFs implemented visitation restrictions for care recipients' families and friends [26]. While effective in reducing infection rates and lowering morbidity and mortality rates, these restrictions resulted in a breakdown of social interaction between care recipients and their families. On the other hand, the demand for regulatory compliance with infection risk reduction measures (e.g., social distancing) [27] and a shortage of essential resources (e.g., protective equipment) [28] significantly strained care routines in RACFs, thereby limiting care recipients' access to routine healthcare and social support services [29]. The ensuing impact of the COVID-19 pandemic and its associated restrictions has been substantial, affecting RACFs, their resident care recipients, and care staff [4,25]. During the pandemic, care staff face numerous challenges in providing care to PWD due to the demand for regulatory compliance with infection risk reduction measures, including physical and social distancing [29,30]. Many staff are grappling with confusion due to unclear guidelines, rapid changes in guidance [31], and a shortage of essential resources such as protective equipment [32,33]. A survey conducted in May 2020 revealed that 43% of nurses felt unprepared for the COVID-19 outbreak [34]. These challenges were further complicated by shared communal spaces and close-contact living environments in RACFs [35]. Moreover, many care staff experienced emotional strain, physical exhaustion, and concerns about contamination while providing care to extremely frail people [36,37].

Particularly, PWD has experienced a multidimensional impact from COVID-19 restrictions, manifesting in heightened levels of agitation, depression, anxiety, and other neuropsychiatric symptoms [38]. Prolonged confinement, along with notable delays in addressing other health conditions [39], adversely affected the physical and mental health of PWD [40], leading to feelings of isolation, loneliness, and boredom among the care recipients [4,41]. Given this context, it is crucial to understand how the COVID-19 pandemic has influenced the prevalence of agitation in dementia

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within RACFs in Australia. Despite the acknowledged impact [16], there is a lack of empirical evidence to demonstrate the extent and nature of the impact of the COVID-19 pandemic on agitation symptoms among PWD living within Australian RACFs.

This study aims to address this gap in existing literature. Our primary objective is to gain valuable insights into the impact of the COVID-19 pandemic on the prevalence of dementia and agitation in dementia within RACFs in Australia. This knowledge will support policymakers, healthcare professionals, and care staff to design targeted care interventions and support mechanisms to promote the overall health and well-being of PWD in RACFs, ensuring that their specific needs are effectively met.

2. Materials and Methods

Study design

This is a retrospective study on secondary analysis of electronic health records (EHRs) from a large, aged care organization running 40 RACFs in New South Wales and Queensland, Australia. The care recipients living in these RACFs were assessed for dementia and agitation in dementia before (2019) and during the pandemic (2020 and 2021) during the same data collection period each year: January to October.

Ethics approval

This study was approved by the Human Research Ethics Committee of the University of Wollongong (Registration number 2019/159).

Datasets

Three de-identified datasets were collected from the participating RACFs: nursing progress notes, medical diagnosis, and demographic data. The nursing progress notes comprise 2.23 million unstructured, free-text entries diligently recorded by registered nurses or enrolled nurses between January 2019 and December 2021. These notes provide chronological records of the care services provided to care recipients over time, observations of their health, and activities of daily living made by the care staff. However, the 2020 dataset only contains data collected from January to October, missing data from November to December. Therefore, we include the data collected from January to October each year to ensure a comparable timeframe for data analysis.

The medical diagnosis dataset comprised 79,500 structured diagnostic notes that were recorded by medical doctors, specialists, allied health or other healthcare professionals who perform diagnostic procedures or interpret the results of diagnostic tests. The demographic data comprises details such as gender and age. A masked unique resident identifier, known as the client ID, was used consistently across all three datasets, allowing linkage of data at individual levels.

Data processing

Identification of care recipients with dementia

Medical diagnosis was used to identify care recipients with dementia. Healthcare professionals employed four specific diagnostic codes to accurately identify and classify care recipients with dementia: Code 500 for dementia and Alzheimer’s disease (including various subtypes such as early onset, late onset, atypical, mixed type, or unspecified), 510 for vascular dementia, 520 for dementia in other diseases, and 530 for other dementias.

Identification of agitation in dementia

As agitation in dementia was only documented in the free-text nursing progress notes, we applied a rule-based NLP algorithm that we developed [7] and was further refined for data extraction. The algorithm refinement involved training the algorithm with 1,000 nursing notes that

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were manually coded by aged care domain experts. Within this dataset, 680 nursing notes documented instances of agitation in dementia (positive rules), the remaining 320 notes did not contain agitation instances. The algorithm achieved a sensitivity of 92.7%, a specificity of 87.3%, and an F-score of 96.3%.

We executed the Python language (Python version 3.9) in conjunction with the open-source data analysis and manipulation library Pandas (version 1.5.3) [42], applying our published method [43]. First, we conducted data preprocessing to eliminate (1) irrelevant or duplicate notes, (2) non-alphanumeric characters and punctuations, and (3) stop words, such as “a”, “the”, is”, and “are” using the Python library Natural Language Toolkit tokenizer. Second, we conducted rule-based NLP to extract any agitation symptoms for care recipients with dementia. The rules were the diverse language patterns used to describe all types of agitation symptoms. The algorithm made use of the spaCy (version 3.0) [44] and scispaCy (version 0.4.0) libraries [45], with the scispaCy library being specifically designed for processing clinical text. The models utilized in scispaCy are pre-trained on gold standard datasets we developed, as described above.

Statistical analysis

The Chi-square test was employed to evaluate the statistical significance of the presence of documented care recipients over a three-year period. Descriptive statistics were employed to examine dementia and agitation prevalence before and during the pandemic. To identify significant differences in prevalence between years within sub-population groups, a Chi-square test was employed. Additionally, within the dementia care recipients, we further investigated the changes in agitation symptoms through the Chi-square test. A paired t-test, executed with IBM SPSS Statistics (version 28) [46], was employed to assess variations in record-taking patterns before and during the pandemic. Furthermore, a content analysis approach was employed to investigate the factors contributing to care recipients' absence during the years 2020 and 2021. Specifically, the last ten nursing notes for each client were thoroughly examined to identify explicit reasons articulated by care recipients or healthcare providers for their departure. The chi-square test was subsequently employed to ascertain whether there were statistically significant changes in client numbers between these two years.

3. Results

Significant changes in gender distribution were observed in 2021. Males exhibited a significant increase of 2.52% compared to both 2019 and 2020 ($p < 0.05$), whereas females experienced a significant decrease during the same period (Table 1). No consistent changes were observed regarding the care recipients’ age distribution over the three years.

Table 1. Comparison of prevalence of dementia and agitation in dementia during the COVID-19 pandemic: number and percentage, by gender and age.

Demographics	Before COVID-19	During COVID-19	
	2019	**2020**	**2021**
No. of care recipients (%)	**n=3,528 (100%)**	**n=3,495 (100%)**	**n=2,692 (100%)**
Sex			
Male	1,261 (35.74)^a	1,249 (35.74)^a	1,030 (38.26)^b
Female	2,267 (64.26)^a	2,246 (64.26)^a	1,662 (61.74)^b
Age group (yrs)			
40 - 65	108 (3.06)^a	108 (3.09)^a	79 (2.93)^b
66 - 75	414 (11.73)^a	456 (13.05)^b	274 (10.18)^c
76 - 85	1,010 (28.63)^a	1,049 (30.01)^a	712 (26.45)^b
86 - 95	1,645 (46.63)^a	1,600 (45.78)^a	1,285 (47.73)^b

95+	351 (9.95)^{a}	282 (8.07)^{b}	342 (12.70)^{c}
No. of care recipients with dementia (%)	**n=1,556 (44.10)^{a}**	**n=1,615 (46.21)^{a}**	**n=1,134 (42.12)^{b}**
Sex			
Male	553 (43.85)^{a}	594 (47.56)^{a}	448 (43.50)^{b}
Female	1,003 (44.24)^{a}	1,021 (45.46)^{ab}	686 (41.28)^{b}
Age group (yrs)			
40 - 65	29 (26.85)^{a}	30 (27.78)^{a}	26 (32.91)^{b}
66 - 75	145 (35.02)^{a}	178 (39.04)^{b}	110 (40.15)^{c}
76 - 85	476 (47.13)^{a}	536 (51.10)^{b}	315 (44.24)^{c}
86 - 95	774 (47.05)^{a}	772 (48.25)^{a}	544 (42.33)^{b}
95+	132 (37.61)^{a}	99 (35.11)^{b}	142 (41.52)^{c}
No. of care recipients with dementia in agitation (%)	**n=1,228 (78.92)^{a}**	**n=1,104 (68.36)^{b}**	**n=667 (58.82)^{c}**
Sex			
Male	440 (79.57)^{a}	417 (70.20)^{a}	260 (58.04)^{b}
Female	788 (78.56)^{a}	687 (67.29)^{b}	407 (59.33)^{c}
Age group (yrs)			
40 - 65	21 (72.41)^{a}	14 (46.67)^{b}	10 (38.46)^{c}
66 - 75	118 (81.38)^{a}	129 (72.47)^{b}	65 (59.09)^{c}
76 - 85	390 (81.93)^{a}	385 (71.83)^{b}	180 (57.14)^{c}
86 - 95	604 (78.04)^{a}	513 (66.45)^{b}	326 (59.93)^{c}
95+	95 (71.97)^{a}	63 (63.64)^{b}	86 (60.56)^{c}

Note: Different superscript labels, a, b, and c, represent significant differences from the chi-square test among the respective years: 2019, 2020, and 2021 ($p < 0.05$).

3.1. Changes in the prevalence of dementia during the COVID-19 pandemic

Significant reductions in the overall prevalence of dementia were observed only in 2021, with a 1.98% decrease compared to 2019 and a 4.09% decrease compared to 2020 ($p < 0.05$) (Table 1). Similar changes were observed in the gender-specific prevalence of dementia, with males experiencing a significant reduction of 0.35% in 2021 compared to 2019 and a 4.06% significant reduction compared to 2020 ($p < 0.05$); females showed a significant reduction of 2.96% in 2021 compared to 2019, and 4.18% compared to 2020 ($p < 0.05$).

Regarding the age distribution, there was a significant increase in the prevalence of dementia across age groups ranging from 40 to 75 over the three years. Specifically, the younger-onset dementia in the 40-65 age group displayed a significant increase of 6.06% ($p < 0.05$), while the 66-75 age group experienced a significant rise of 5.13% from 2019 to 2021 ($p < 0.05$). The other age groups showed random variations in dementia prevalence without consistent trends over the three years.

3.2. Changes in the overall prevalence of agitation in dementia during the COVID-19 pandemic

A Significant reduction in the prevalence of agitation in dementia was observed over the three years, exhibiting a significant decrease of 20.1% from 2019 to 2021 ($p < 0.05$) (Table 1). A similar change was observed in the gender distribution during the same period. Specifically, males with dementia and agitation showed a significant reduction of 21.53% from 2019 to 2021 ($p < 0.05$), while females exhibited a significant reduction of 19.23% over the same period ($p < 0.05$).

Regarding the age distribution, a significant reduction was also observed in all age groups over the three years. The most significant change in prevalence was observed in the younger-onset dementia group (40-65), with a 33.95% decrease in 2021 compared to 2019 ($p < 0.05$). This was followed by 24.79% reductions in the 76-85 age group, 22.29% in the 66-75 age group, 18.11% in the 86-95 age group, and 11.41% in those aged 95 and above, with each decrease also being statistically significant ($p < 0.05$). Additionally, there was a significant decline in dementia care recipients aged 76-95+ and older in the second year of the COVID-19 pandemic, 2021.

3.2 Changes in the prevalence of specific agitation symptoms during the COVID-19 pandemic

A total of 59 agitation symptoms were observed in 2019, which decreased to 39 in 2020 (a reduction of 33.9%), and then further dropped to 34 in 2021 (a 12.82% decrease). The study documented a total of 31 agitation symptoms which were consistently observed in all three years.

A total of eight (25.81%) out of the 31 agitation symptoms exhibited consistent changes, either increase or decrease, over the three years (Table 2). Among these, six symptoms consistently experienced a significant increase from 2019 to 2021: resisting (increased by 28.98%), wandering (increased by 11.78%), restlessness (increased by 3.19%), complaining (increased by 10.1%), arguing (increased by 2.36%), and outbursts (increased by 1.74%) ($p < 0.05$). Conversely, two symptoms showed a consistently significant decrease from 2019 to 2021, specifically pacing (decreased by 15.88%) and speaking in an excessively loud voice (decreased by 10.9%) ($p < 0.05$).

Table 2: Agitation symptoms showing consistent increase or decrease in prevalence during the COVID-19 pandemic

Agitation symptoms	Before COVID-19	During COVID-19	
	2019	**2020**	**2021**
	n=1,228 (100%)	**n=1,104 (100%)**	**n=719 (100%)**
Resisting	546 (44.46)^{a}	495 (44.84)^{a}	528 (73.44)^{b}
Wandering	407 (33.14)^{a}	399 (36.14)^{a}	323 (44.92)^{b}
Restlessness	123 (10.02)^{a}	132 (11.96)^{ab}	95 (13.21)^{b}
Complaining	69 (5.62)^{a}	153 (13.86)^{b}	113 (15.72)^{b}
Arguing	24 (1.95)^{a}	34 (3.08)^{ab}	31 (4.31)^{b}
Outburst	6 (0.49)^{a}	15 (1.36)^{b}	16 (2.23)^{b}
Pacing	224 (18.24)^{a}	29 (2.63)^{b}	17 (2.36)^{b}
Speaking in excessively loud voice	233 (18.97)^{a}	203 (18.39)^{a}	58 (8.07)^{b}

Note: Different superscript labels, a, b, and c represent significant differences from chi-square tests among the respective years: 2019, 2020, and 2021 ($p < 0.05$).

A total of 10 (32.26%) out of the 31 agitation symptoms remained relatively stable over the three years, while 13 (41.94%) exhibited significant but erratic changes, lacking a discernible pattern (as indicated in Appendix A).

3.3 Comparative analysis of the top five prevailing agitation symptoms

The five most prevailing agitation symptoms were resisting, pacing, wandering, speaking in excessively loud voice, and restlessness (Table 2). Table 3 compares the average occurrence of these symptoms per recipient per year.

Two symptoms, resisting and pacing, consistently exhibited significant changes over three years, with no significant gender difference in occurrence frequency. The average occurrence of resisting declined significantly from 2.28 times per care recipient in 2019 to 2.03 times in 2021 ($p < 0.05$), while pacing substantially increased from 1.89 times in 2019 to 4.08 times per resident with the symptom in 2021 ($p < 0.05$). The rest of the three agitation symptoms, wandering, speaking in an excessively loud voice, and restlessness, exhibited significant gender differences in frequency of occurrence. The occurrence of wandering symptoms in males significantly decreased in three years, dropping from

1.98 times per care recipient in 2019 to 1.69 times in 2021 ($p < 0.05$). Conversely, the occurrence of restlessness in females significantly increased from 1.8 times in both 2019 and 2020 to 2.24 times in 2021 ($p < 0.05$). The rest of the symptoms did not exhibit a consistent change pattern.

Table 3: Comparison of the top five prevailing frequently occurring agitation symptoms over three years. Unit of analysis: the number of occurrences per person with the symptom in one year

Agitation symptoms	**Gender**	Before COVID-19	During COVID-19	
		2019	**2020**	**2021**
		n=1,228 (100%)	**n=1,104 (100%)**	**n=719 (100%)**
Resisting	All	^{a}2.28 (1.87-2.66), n=546	^{b}2.13 (1.88-2.38), n=495	^{c}2.03 (1.8-2.27), n=528
Pacing	All	^{a}1.89 (1.45-2.32), n=224	^{b}2 (0.82-3.18), n=29	^{c}4.08 (3.4-4.75), n=17
Wandering	Female	^{a}1.99 (1.75-2.23), n=274	^{b}2.5 (2.21-2.79), n=277	^{c}1.74 (1.49-1.99), n=192
	Male	^{a}1.98 (1.64-2.32), n=133	^{b}1.87 (1.54-2.2), n=122	^{c}1.69 (1.4-1.98), n=131
Speaking in excessively loud voice	Female	^{a}1.71 (1.45-1.97), n=162	^{b}2.07 (1.74-2.4), n=148	^{c}1.9 (1.36-2.44), n=48
	Male	^{a}1.7 (1.3-2.1), n=71	^{b}2.6 (1.91-3.29), n=55	^{c}1 (0.38-1.62), n=10
Restlessness	Female	^{a}1.8 (1.41-2,19), n=82	^{a}1.8 (1.42-2.18), n=86	^{b}2.24 (1.71-2.77), n=68
	Male	^{a}1.5 (1.04-1.96), n=41	^{b}3 (2.13-3.87), n=46	^{c}2.24 (1.71-2.77), n=6

Note: Different superscript labels, a, b, and c, represent significant differences from chi-square tests between the respective years: 2019, 2020, and 2021 ($p < 0.05$).

3.4 Comparative analysis of frequencies of agitation symptom occurrence

More than half of the care recipients experienced agitation symptoms two to five times each year (Table 4). The portion of this cohort of dementia care recipients significantly increased from 50.56% in 2019 to 58.28% in 2021 ($p < 0.05$). In 2019, 27.44% of the dementia care recipients, totaling 337, experienced agitation symptoms once. By 2021, this proportion had significantly decreased by 6.02%, dropping to 21.42% ($p < 0.05$). Additionally, instances of agitation exceeding 20 occurrences significantly declined from 2019 to 2021. Due to incomplete records, we could not decide the destination of these care recipients (as indicated in Appendix B).

Table 4: Frequency of agitation symptoms in dementia care recipients over three years

Frequency of agitation episodes	**No. care recipients (%)**		
	Before COVID-19	During COVID-19	
	2019	**2020**	**2021**
Total	1228 (100%)	1104 (100%)	719 (100%)
1	337 (27.44)^{a}	316 (28.62)^{a}	154 (21.42)^{b}
2 to 5	622 (50.56)^{a}	589 (53.35)^{a}	419 (58.28)^{b}
6 to 10	148 (12.05)	117 (10.6)	96 (13.35)
11 to 15	52 (4.23)	49 (4.44)	35 (4.87)
16 to 20	32 (2.61)	22 (1.99)	14 (1.95)
21 to 25	13 (1.06)^{a}	8 (0.72)^{ab}	1 (0.14)^{b}

25 to 30	10 (0.81)^{a}	2 (0.18)^{ab}	0 (0)^{b}
31 and above	14 (1.14)^{a}	1 (0.09)^{b}	0 (0)^{b}

Note: Different superscript labels, a, b, and c, represent significant differences from chi-square tests between the respective years: 2019, 2020, and 2021 ($p < 0.05$). .

3.5 Changes of number of nursing notes per client between years

To assess whether the care staff consistently recorded the care recipient's health condition and care delivered, we compared the number of nursing notes per care recipient over the three-year observation period for 1,882 care recipients who stayed in the same RACF. In 2020, there was a significant increase of 20 notes per client compared to the year 2019 (2019: mean: 226, 95% confidence interval (CI): 219.45, 231.68; 2020: mean: 246, 95% CI: 243.55, 248.95) ($p < 0.05$). However, in 2021, there was a significant decrease of 111 notes per client compared to the year 2020 (2021: mean: 135, 95% CI: 134.98 to 135.42) ($p < 0.05$). Therefore, the frequency of nursing documentation was not consistent.

3.6 Care recipients' discharge patterns over the three years

Overall, there were no clear discharge patterns for three groups of care recipients over three years, normal care recipients, care recipients with dementia but no agitation, and care recipients with dementia and agitation (Table 5). There is no consistent change for care recipients over three years.

Table 5: Comparison of reasons for discharge from RACFs in three years by clients without dementia, with dementia but without/with agitation

Reasons for leaving RACFs	Year	Without dementia	Dementia without agitation	Dementia with agitation
Deceased	2019	280 (51.66)	88 (66.17)	125 (50.2)
	2020	183 (64.66)	58 (51.79)	172 (53.42)
	2021	194 (43.99)^{a}	40 (67.8)^{b}	92 (41.82)^{a}
Discharge to home	2019	61 (11.25)	25 (8.93)	21 (8.43)
	2020	23 (8.13)^{a}	10 (22.22)^{b}	12 (3.73)^{a}
	2021	76 (17.23)^{a}	17 (28.81)^{a}	13 (5.91)^{b}
Transfer to hospital	2019	38 (7.01)	11 (8.27)	21 (8.43)
	2020	17 (6.01)	13 (11.61)	36 (11.18)
	2021	15 (3.4)^{a}	7 (11.86)^{b}	9 (4.09)^{ab}
Transfer to another RACFs	2019	15 (2.77)	1 (0.75)	6 (2.41)
	2020	3 (1.06)	0 (0)	0 (0)
	2021	8 (1.8)^{a}	14 (23.73)^{b}	19 (8.64)^{c}
Not decidable	2019	148 (27.31)^{a}	8 (6.02)^{b}	76 (30.52)^{a}
	2020	57 (20.14)	31 (27.68)	102 (31.68)
	2021	144 (32.65)	19 (32.2)	68 (39.55)

Note: Different superscript labels, a, b, and c, represent significant differences from chi-square tests between the respective years: 2019, 2020, and 2021 ($p < 0.05$).

4. Discussion

This study aimed to investigate the impact of the COVID-19 pandemic on the prevalence of dementia, and agitation in dementia for care recipients living in Australian RACFs. The changes in the prevalence of dementia and agitation provided several important insights but also raised important considerations and limitations that should be discussed.

Previous research identified a significant association between the common risk factors for dementia, such as aging, frailty, and comorbidity, with COVID-19 infection and adverse outcomes [47]. Dementia has accounted for a significantly higher proportion of the mortality rate during the COVID-19 pandemic. However, this reported trend did not apply to our cohort of study population. Not alone, our finding that there was not a direct relationship between dementia rates and COVID-19, was seconded by the conclusion of a systematic review [48]. Similarly, AIHW also reported a relatively stable proportion of dementia care recipients in RACFs, which were around 54-55% between the pre-COVID-19 period (2017–18) and during the COVID-19 period (2021–22) [12].

There was a significant decline in dementia care recipients aged 76-95+ in the second year into COVID, 2021. This decline may be explained by the increased risk of COVID-19-related mortality with PWD aged over 80, as observed by Tahira et al [49]. A contrasting trend emerged among the younger-onset dementia group, with a marginal rise in 2020 and a significant surge of 6.06% in 2021. These findings agreed with those of the AIHW, which documented a progressive escalation in the number of care recipients with younger-onset dementia residing in RACFs over the preceding years [50]. It is plausible that the unique stressors, disruptions in healthcare services, and societal upheavals induced by the pandemic may have contributed to the observed rise in prevalence. This observed significant increase calls for further healthcare planning, resource allocation, and formulation of strategies to address the unique needs of younger-onset dementia in the context of pandemic-induced challenges.

It is important to note that the overall prevalence of agitation in dementia decreased during the COVID-19 pandemic (2020-2021). One possible reason could be the reduced frequency of nursing notes recorded by nursing staff. In normal situations, nurses may allocate a considerable portion of their work time to EHRs documentation, ranging from approximately one-quarter [51] to over one-third [52]. The heightened workload due to the infected care staff refraining from returning to RACFs [53] contributed to a notable decline in the thorough documentation and monitoring of agitation symptoms. Another reason that may have caused reduced documentation of agitation symptoms may be that the care recipients were confined to their bedrooms and had much less opportunity to sit together with the other care recipients in the common room, which reduced the opportunity for the busy care staff to observe their behaviors. The implementation of infection control measures, such as restricted visitation, increased hygiene practices, and isolation protocols [54], may have also created a calmer and less stimulating environment, reducing triggers for agitation among dementia care recipients. However, this silence is not good for health, as demonstrated by the increasing occurrence of specific agitation symptoms such as resisting and wandering in during the COVID-19 pandemic (2020-2021). Our findings are in accordance with the findings of Leontjevas et al. [55] and Kuroda et al. [56].

Resisting behaviors in PWD signals communication breakdown due to a lack of understanding of care needs or misinterpretation of caregiver intentions [57]. In our study, COVID-19-related behavioral restrictions may have contributed to an increase in aggression, with significant rises in various physically aggressive behaviors -including fighting, hitting, and biting observed during the pandemic compared to 2019 (Appendix B Table 2). This finding follows recent research highlighting a surge in aggressive behaviors amid the pandemic [55,58,59]. Our study extends the understanding of aggression to include not only physical but also verbal manifestations. Kuroda et al. reported a higher prevalence of verbal abuse between dementia care recipients and caregivers during the COVID-19 pandemic, with a 2.3% increase. We also find the prevalence significant increase in the use of shouting and abusive language, and a slight increase in the use of profane language in 2020 compared to 2019 (Appendix B Table 2). The elevated level of verbal aggression appears to be indicative of the significant stress experienced by PWD in response to changes in their living environment, a stressor that can manifest even in the early stages of cognitive decline [60]. The escalation of verbal abuse and violence places an additional burden on caregivers, emphasizing the complex dynamics involved in dementia care during the pandemic.

Previous research identifies an increased prevalence of emotional distress among PWD in RACFs during the COVID-19 pandemic. These include increased levels of anxiety [61,62], low mood [62], irritability [59], apathy [59] and depression [61]. Specifically, studies have found a surge in irritability within six to ten weeks following the initiation of quarantine measures associated with the COVID-19 pandemic [38]. Our research aligns with these observations, revealing an increase in anger (3.07%), irritability (2.72%), and outbursts (0.87%) in 2020 compared to the preceding year, 2019 (Appendix B Table 2). The concordance between our findings and prior research underscores the pervasive impact of pandemic-related measures on the emotional well-being of PWD. Comprehensive dementia care strategies should encompass not only physical health but also the emotional and psychological well-being of PWD, particularly in the context of public health crises.

Our data provides a comprehensive overview of the outcomes of the documented care recipients with dementia and agitation in terms of deceased, discharge to home, and transfers to hospital and other RACFs during COVID-19. This information reveals the dynamics of exits, particularly distinguishing between those with and without dementia. Firstly, focusing on care recipients with dementia, the data reveals a notable shift in outcomes during the pandemic. The increased mortality rate from 51.66% to 64.66% from 2019 to 2020 signifies a substantial rise in mortality rate among people without dementia. This finding aligns with broader observations of increased vulnerability and adverse outcomes for PWD during the COVID-19 pandemic [11,63–65]. However, the mortality rate for this population dropped to the lowest in 2021, 43.99%. This may be attributed to increased awareness and preventive strategies in place in the second year into the pandemic. Interestingly, the mortality rate for PWD without agitation dropped in the first year, then recovered to the pre-pandemic level in the second year of the pandemic. Conversely, the mortality rate for PWD with agitation significantly dropped the second year into the pandemic, in 2021.

PWD, but no agitation was the largest group to be sent back home during the pandemic. Conversely, PWD with agitation had the least opportunity to return home. The first year into the pandemic, the PWD had a much higher rate of transfer to hospitals compared with themselves before the pandemic and compared with the people without dementia. This may be indicative of the increased severity of health conditions or the need for specialized medical attention for PWD during the pandemic [66, 67]. It also reflects the strain on RACFs to manage complex health situations within their facilities, necessitating transfers to hospital settings. While the situation stabilized for PWD without dementia, the transfer rate significantly dropped down for those without dementia or those with dementia and agitation in dementia in the second year of the pandemic. Although there was a reduced transfer rate for care recipients without dementia to other RACFs in the first year of the pandemic (2020), the transfer rate for PWD was significantly increased, 23.73% for PWD with agitation, and PWD without agitation (8.64%) in the second year of the pandemic (2021).

We acknowledge several limitations of this study. Firstly, because we only had access to nursing notes recorded from January to October for the year 2020, we confined our comparative data analysis among three years to this period, which does not fully capture the demographic data over the three years, which might reduce the generalizability of findings. Secondly, missing records in gender and age caused the exclusion of these records from analysis, limiting the comprehensive understanding of the care recipient profile. Thirdly, this observational study in the natural setting did not account for any potential confounding factors that could influence the observed outcomes, making it impossible to discern the causality of the observed changes. Despite knowledge about individual characteristics of dementia care recipients, such as cognitive impairment severity, comorbidities could contribute to variations in dementia prevalence and agitation, which this study did not dig deep into [56]. Fourthly, although the study focused on examining the prevalence of agitation among dementia care recipients before and during the COVID-19 pandemic, it did not thoroughly investigate the underlying reasons for the observed changes in agitation. Factors such as alterations in routine, stress levels, and modifications in physical activities could potentially contribute to

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fluctuations in agitation symptoms. The lack of in-depth exploration of these factors limits our understanding of the specific mechanisms driving the changes in agitation observed during the pandemic. Finally, the findings of this study are based on data collected from 40 RACFs and their representativity of all RACFs in Australia or in other countries, hence the generalizability of the results is yet to be established.

Despite limitations, this study provides valuable insights into the changes in agitation prevalence among dementia care recipients in RACFs before and during the COVID-19 pandemic. Future studies can improve upon our research by extending the data collection period to include post-pandemic phases, offering a more comprehensive understanding of trends and potential recovery among PWD in RACFs post-COVID-19. This extension would allow for the exploration of long-term effects and evolving patterns in agitation symptoms. Additionally, integrating data on interventions and causal factors, such as changes in care protocols or caregiver-care-recipient interactions, would enrich the analysis, contributing valuable insights and aiding the development of targeted interventions.

5. Conclusions

This study examined the impact of the COVID-19 pandemic on dementia prevalence and agitation among care recipients in Australian RACFs. It did not identify a significant association between dementia prevalence and the COVID-19 pandemic, although dementia prevalence showed nuanced patterns. The overall agitation prevalence was significantly decreased during the COVID-19 pandemic. The five most frequently occurring agitation symptoms were resisting, pacing, wandering, speaking in excessively loud voice, and restlessness. Future research should extend data collection, considering interventions and causal factors for a more comprehensive understanding.

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